Behaviour and Sensory
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Parents of a child with a chromosome or genome disorder face many hurdles - to find and access the right treatment, support and education for their child. This is in addition to coming to terms with their child’s disability and the effect it has on the rest of family life. Parents often judge themselves harshly and feel as if they have failed in some way if their child does not ‘behave’ like other children. If the behaviour problems are severe it can be difficult to see the child in a positive light. Sometimes that can affect the parent-child relationship to such an extent that it becomes impossible to separate the ‘positive’ behaviour from the ‘negative. It is important to think about what your child does well - perhaps smiles at people, sits still while watching TV or holds a spoon. It could be any number of small achievements. Then look at what you have done. You have given your child a loving home where they are cared for, loved, have an education and feel secure. No one else in your child’s life will ever know or understand them as well as you do. If you feel positive about yourself and your child then it will allow you to see when changes to behaviour happen. In many cases, challenging behaviour occurs because the person with a learning disability is frustrated at his or her inability to make others understand what he or she needs or wants. Your child might, at some time in their life, show signs of a behaviour that is either unusual or difficult to manage. Many of these behavioural issues come under the title ‘challenging behaviour’. For many children with a particular chromosome or genome disorder some of these behaviours are often well documented. But for others, a ‘behavioural issue’ might be new in that child and could arrive at any age. For many children with a particular chromosome or genome disorder some of these behaviours are often well documented. But for others, a ‘behavioural issue’ might be new in that child and could arrive at any age. Challenging behaviour can include aggression, self-injury, destructiveness and disruptiveness. Some children with a chromosome or genome disorder may have challenging behaviour in their early years, that improves as they get
older and are supported to develop better communication skills. For others it can develop as they get older.

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Babies, children, and adults behave in a certain way because.....

- They learn that their actions will give them a response or a reward.
- They have a need, preference or desire to communicate.
- They have a medical, emotional or physical need that leads to the behaviour or keeps it going.
- They have a sensory sensitivity.

Sudden changes in behaviour may indicate that there is an undiagnosed medical, physical or emotional problem. This can happen at any age if the individual has communication difficulties. For example, a child might start to bang their head or cry all the time if they are in pain or having hearing difficulties? An adult may become unusually aggressive or begin hurting themselves. It is important to check that your child does not have any physical or medical problems first and foremost.

**Behavioural Difficulties: What do we mean?**

**Types of behaviour**

- Physical (biting, hitting, kicking, pinching, pulling hair, slapping, spitting).
- Aggression – Non-physical (screaming, shouting, tantrums, yelling).
- Destruction (damaging or throwing things, ripping clothes, smearing).
- Eating inedible objects (pica).
- Rocking.
- Running off, or away.
- Self injurious behaviour (biting, pulling hair, head-banging, self-hitting, skin picking and many more forms).

The child who showed the behaviour might even be picked up and talked to for a few minutes. This can be quite a rewarding experience for the child that showed the behaviour; so much activity and noise. A child will quickly learn that if they are bored, biting someone close by will produce a very interesting result. If they bite themselves, it is likely that someone will check for damage, maybe bathe any wounds, and bandage it, so that child is rewarded with increased attention, i.e. more attention.
Behaviour becomes a problem when it:

- Hurts the person or someone else.
- Prevents the person from being included.
- Stops personal development.
- Causes major disruption to family life.
- Is socially unacceptable.

All parents at one time or another have problems with their children regardless of whether they are disabled or not. There may be difficulties at play, meal, bed or bath time; with going out, toileting; or their children may hit out, bite or push. Behaviour is sometimes described as ‘challenging’.

What does this mean?
Generally it is a description of actions that could be seriously damaging to the person themselves or others, or to their environment: kicking, biting, throwing objects, smearing contents of a nappy, throwing food or drink about, running off, destroying furniture or property. It might also mean endless crying, screaming, chewing on objects, wandering about, not sleeping or eating properly, taking off clothes, fiddling with parts of the body, self-injuring, rocking or shaking and so on. Behaviour may not always be challenging but if it is repeated constantly and for no apparent reason then it can be very difficult and frustrating for parents to manage.

“Always try to use a positive rather than a negative if you can. I find that by saying NO to my son, he just laughs or ignores me, but if I say STOP! in a firm voice, he takes me more seriously. If your child does something quite aggressively; try saying the word GENTLE or GENTLY in a soft voice, or sing certain words to them. It might work for some children/adults.”
Why does it happen?

Certain behaviours happen for an obvious reason. Babies learn to cry loudly when hungry, wet or bored because they have learned that crying gets them what they want or need. As children grow they learn how to behave; because they learn that their behaviour gives them access to what they need or what they want through how the behaviour is responded to by others. If a child has difficulty with speech or cannot use sign language or has very little understanding, then behaviour becomes the only way a child can show a parent what is needed.

“My son will often scratch at his face, mouth or his hands when he becomes cross and agitated. I found that using white prescription gloves and the scratch sleeves (www.scratchesleeves.co.uk) we purchased, helps a lot during melt downs. If he scratches at his face whilst he has the scratch sleeves on, due to the mitts being made of silk he will not cut or harm his skin. We particularly use them when going into new surroundings to protect him if he becomes agitated or upset. This technique has worked well for us.”
PAIN AND DISCOMFORT

Don’t forget to ask yourself if your child could be teething, or have toothache.

Babies use their mouth to explore objects because it gives them a lot of information. Chewing and biting can also help to develop muscles in the mouth that are used to form sounds. Try a safer alternative to your arm or leg, like a soft toy or teething ring.

A child can learn to behave in a ‘challenging’ way for other reasons. The real difficulty is trying to understand why and what ‘message’ a child is sending out.

Parents find it very hard to deal with unusual behaviour that happens ‘out of the blue’ and start to think that it is all part of a child’s personality and nothing can be done about it. Often parents have learned to react to these behaviours in a certain way and do not realise that perhaps their reactions are allowing the behaviour to occur again and again, or reinforcing negative behaviour patterns.

Your child might have earache, toothache or another pain. Take them to see their GP, Paediatrician or dentist to get them fully checked over.

Pain can make anyone behave in a different way.
Why is challenging behaviour more common in some syndromes?

Some types of behaviour are known to be more common in some well known syndromes. But in many children/adults, the cause of that behaviour is usually not simply because they have a chromosome disorder. Pain/discomfort and impaired communication skills that arise from the disorder are much more likely to be at the root of the behaviour. It is important to understand that these behaviours are not inevitable and interventions can be helpful.

**Pain and discomfort should always be ruled out in the first instance before trying any behavioural approaches.**

An early diagnosis, from the geneticist or paediatrician, should include a description of behaviours that might be associated with the disorder and help to identify the best approach to managing them. This would require a multi-disciplinary team approach involving one or more professionals such as: behaviour, educational or clinical psychologists; social workers; psychiatrist; GP; physiotherapist; speech and language therapist; or occupational therapist. If your child is in school then the SENCO or their teacher could also be involved. Parents can seek advice and help from their local Child Development Centre, Portage service, Health Visitor or school.

If a child has autism then that can add to their challenging behaviour.

If you suspect that your child might have an autistic spectrum disorder then it is important to have an assessment done, because there are specific ways to help a child with autism, manage their behaviour.

Please go to page 27 to read more about Autism and sensory sensitivities.

[Circled Marks from biting]
Self-injurious behaviour
What is self-injurious behaviour? It is when someone intentionally harms their own body, such as cutting or biting themselves. It’s often a way to cope with emotional pain, intense anger and frustration. Or to meet sensory processing needs.

Self injurious behaviour in children with intellectual disability
http://bit.ly/1OvOcjk
A research paper written by Prof. Chris Oliver, Dr Louise Davies and Dr Caroline Richards. Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham.
This paper has been written to help parents and carers of children with an intellectual disability to understand what self-injury is, what the causes are and which interventions are effective. The briefing focuses on children with profound to moderate intellectual disability, who may also have autism spectrum disorder or a genetic syndrome.

The Challenging Behaviour Foundation has an information sheet about self-injurious behaviour written by Glynis Murphy, Tizard Centre, University of Kent can be read/downloaded here:
http://bit.ly/2mPWAiQ

The Autism research institute of America
Written by Stephen M. Edelson, Ph.D.
An information guide called Understanding and Treating Self-Injurious Behaviour.

Hand biting ➔
What can parents do?
A child may have a number of behavioural problems or just one. You have to decide which one of these problems needs the most urgent attention. It is impossible to stop everything all at once. It will take time and energy and effort; there is no on/off button or magic wand. You have to choose the one behaviour that causes the most difficulty and start working on that. If you want to change your child’s behaviour then you have to find out why a child behaves in a certain way. Usually parents see a Behavioural or Clinical Psychologist to discuss any problems, but there are often long waiting lists. There are ways to help this process along and parents can look at what a child does immediately before, during and after a particular behaviour. A psychologist will talk to you about the problem behaviours that most concern you so that they can assess the reasons why the behaviours may be occurring. If there is no obvious reason why it happens, then they will carry out an assessment, known as a functional analysis. This will involve a detailed interview with you; home and school observations and the recording of the behaviours. You will be asked to record on a sheet of paper when a particular behaviour occurs. You will also be asked to note down what happens just before the behaviour, what exactly the behaviour was, and what your reactions were immediately afterwards. This record is known as the ABC chart.
**ABC Chart**

Antecedents - what happens directly before the behaviour occurs.

Behaviour - what the behaviour was.

Consequence - what happened after the behaviour occurred.

You observe your child’s behaviour for several weeks and look to see if a pattern emerges. It may be something very simple. E.G. a child who would not leave an activity to go out would have a chart that looked like this.......

<table>
<thead>
<tr>
<th>DAY, DATE, TIME</th>
<th>WHAT HAPPENED JUST BEFORE?</th>
<th>WHAT WAS THE BEHAVIOUR?</th>
<th>WHAT HAPPENED AFTERWARDS?</th>
</tr>
</thead>
<tbody>
<tr>
<td>17/01/17 Monday 10.00 am</td>
<td>Jay is watching a video</td>
<td>When Jay is asked to get ready to go out, he screams and has a tantrum</td>
<td>Mum switched off the TV and yelled at Jay. Jay carried on screaming. Mum gets angry and holds Jay until he stops.</td>
</tr>
</tbody>
</table>

The record sheet shows there was no ‘warning’ given to Jay that it was time to go out. Some children need time to absorb change. Timetables help children understand what is going to happen next. The timetable could be a visual picture showing a clock and then the activity – shopping, library, school etc. A small cooking timer set to ten minutes can help a child to understand, that when the buzzer goes off it is time to stop the activity. If you can start recording this information about your child’s behaviour before you see a psychologist it will help the assessment and save time. If you can start recording this information about your child’s behaviour before you see a psychologist it will help the assessment and save time.
GOLDEN RULES

- Children behave in a certain way for a reason. The difficulty is that we may not understand or know what that reason is and we see the behaviour as a problem.
- Try to think of the behaviour as a ‘message’ that your child is sending to you.
- Reward good behaviour. Behaviour that is rewarded tends to be repeated. It may not be obvious that you are giving a reward.
- Don’t forget to reward or praise a child when they are showing desirable behaviour, perhaps just sitting quietly or watching the TV. The key is to identify what your child finds rewarding and then to use that to reinforce desirable behaviours.
- Stop dangerous or harmful behaviour. If behaviour is dangerous or harmful to others or to your child, it must be stopped. You can take precautions to safeguard a room or protect yourself and your child.
- Anticipate problems. If your child likes to bite, offer an alternative object for the child to bite on – a teething toy or rubber tube. If they kick out at everyone, remove their shoes, or use soft slippers. Offer a cushion or large soft toy as an alternative.
- Give children time to process information and time to absorb new information. A visual timetable, where pictures or symbols represent activities at certain times of the day, may help your child to accept change.
- Give your child enough time to understand your instructions. Sudden change can be very difficult for children. They need enough warning that an activity is about to end. Ten minutes, five minutes, and one-minute warnings for example are helpful. Egg-timers are ideal for this.
- Distraction helps. If your child is having a tantrum, or will not leave the room or listen to you, offer them an interesting alternative to the behaviour or activity that you want to stop. This works well with some younger children. “Look I have just seen a green fairy with red boots dancing up the stairs!! Let’s go look for it!” will attract their attention and usually stop the behaviour. If your child has communication difficulties then sometimes the distraction will have to be more visual: a glove puppet, silly hats that you can put on, or singing songs in funny voices. Take the child’s attention away from the particular activity you want to stop.
- Try to be consistent and persistent. Once you have decided to
ignore a behaviour and not reward it, if you give in or lose your temper then your child will continue to use that behaviour – because it works.

- Use simple ‘this first then…’ language, augmented by symbols, object referencing and basic sign language if possible. I.e. show your child his/her coat and say: ‘Coat on first, then car.’

**CONTACTING A MEDICAL PROFESSIONAL**

If you have concerns about your child’s behaviour then there are several ways to get help.

- Contact your GP who can refer you to a local Child Development Centre.
- If your child is in school then many Local Education Authorities (LEAs) will have specialist teams that advise on behaviour management. Your school will have contact information.
- The Child and Adolescent Mental Health Service (CAMHS) offers a comprehensive range of services and can provide help and treatment to children and young people who are experiencing emotional or behavioural difficulties, or mental health problems, disorders and illnesses. Some of these services are based in NHS settings, such as Child and Family Consultation Services, in-patient and outpatient departments of hospitals, GP surgeries and health centres. Others are based in educational settings such as schools, colleges and universities, or in youth centres. Although it is usual for a GP to refer young people to this service it may be accessed through your Health Visitor, Community or School Nurse, your child’s school, a social worker or a health professional. It is sometimes possible to contact them directly. There can be a bit of a waiting list for CAMHS, so the sooner you get referred, the quicker your child will be seen.

**Medication**

A range of medications has been widely used to treat self-injury in individuals with an intellectual disability, including those typically used to treat anxiety, depression, epilepsy and psychosis. Generally, interventions based on Applied Behaviour Analysis should always be tried before medication, if medication is to be used at all. Given the numerous and potentially harmful side effects of such medications, they should be prescribed as a last resort and their effects very carefully monitored.
NICE (The National Institute for Health and Care Excellence)
Evidence-based statements to deliver quality improvements in the care of people with a learning disability and behaviour that challenges. On the NICE website there is an interactive flow chart that helps you to develop a support plan, see: http://bit.ly/2vfbTac
As well as this flowchart there are several other flowcharts on the website aimed at children or adults, and different types of behaviour.

PICA
What is Pica?
Pica is the eating of non-food inedible items, such as stones, faeces, clothing, sand, snails, dirt, etc. Most young children go through a stage of picking up things they shouldn’t to put in their mouths, like sand and dirt etc, for them it is just a way of finding out about the world around them by ‘mouthing’ everything. But there are many children and adults with a chromosome or genome disorder that carry on eating things they shouldn’t. This behaviour, called pica, may be a sign that the child has a developmental, behavioural, emotional, nutritional or health problem. Some children who have pica have low levels of iron or zinc in their bodies. The risks of pica can be choking, vomiting, infections, blockages and poisoning. It could be sensory, or an attention issue. It is best to get your child or adult checked out with your GP for any health problems, or if you are really concerned go to your local walk-in or urgent treatment centre for advice. The Challenging Behaviour Foundation have a useful guide on Pica on their website. (see links page 20)

“We use Chewelry. They are silicone chewable shapes on a necklace or keyring, which provide a safe way of gaining comfort when teething. Our little one has a habit of chewing anything she can get her hands on and has even bitten through buttons on her school uniform. You can get Chewelry from several websites including Amazon and Ebay.”
**STIMMING**

Stimming is a self-stimulating behaviour such as flapping, rocking or spinning round and round and can be a harmless way of relaxing. For a child or adult who stims non-stop though, it could hold back their learning; because they are so focused on their stimming behaviour. Other stims can be self-injurious (Head banging or repeatedly hitting themselves in the head or face, are extreme forms of stimming).

Why many of our children behave in this way is difficult to understand. Many children and adults with a chromosome or genome disorder have high pain thresholds. i.e. they don’t always feel pain, like most people would. The sensation they feel from hitting themselves might actually be quite comforting or pleasing, or a tolerable discomfort that distracts them from their anxiety or pain.

**VERBAL STIMMING**

What is verbal stimming? - this is when your child uses their mouth to make noises, for example blowing raspberries, humming or repeating the same word or words over and over again. For tips on how to change your child’s verbal stimming see: http://bit.ly/2lgWyoe and http://bit.ly/2bfMdmD

“My daughter loves to pick up books and fan the pages. She has always and still does love to spit water like a fountain and has a fascination with sticks, sand and stones, she will pick up stones between her forefinger and middle finger (like a scissors), and she is able to imitate a dogs bark, her and the neighbour’s dog regularly bark at each other almost as if in conversation.”
ANXIETY
Anxiety is something we all experience from time to time. It is a normal response to situations that we see as threatening to us, for example, sitting an exam, it would be natural to feel anxious. However, anxiety can be unhelpful as......

- The symptoms can be uncomfortable
- The symptoms can be frightening if someone doesn’t know that these are signs of anxiety
- It can lead people to worry that there is something wrong with them.

When anxiety goes on for a long time, specialist help may be needed. People with a learning disability may become anxious at various points in their life. Stressful life events and times of transition, e.g. changing schools or leaving school, starting at college or a day-care centre, changes in staff support, moving home or a change in family dynamics are some possible causes, but anxiety may also occur for no obvious reason.

SEPARATION ANXIETY
Separation anxiety and fear of strangers is a very common in most children when they are babies/toddlers. Babies and toddlers often get clingy and cry if you leave them, even for a short time. It is a normal part of your child's development and they usually grow out of it. However for some children and adults with a chromosome or genome disorder they don’t grow out of it. As they get older and their awareness of the world around them increases, they can feel unsafe or get upset in new situations.

Separation anxiety disorder is NOT a normal stage of development, but a serious emotional problem characterised by extreme distress when a child is away from their primary carer. However, since normal separation anxiety and separation anxiety disorder share several symptoms, it can be difficult to figure out if your child just needs time and understanding or has a more serious problem. The main differences between healthy separation anxiety and separation anxiety disorder are the intensity of your child’s fears, and whether these fears keep him or her from normal activities. Children with separation anxiety disorder may try to avoid attending school or family events.
They might be reluctant to go to sleep or have nightmares or complain about feeling sick or have a headache or tummy ache.
The following are common causes of separation anxiety disorder in children:
- **Change in environment:** In children prone to separation anxiety, it is possible that changes in surroundings, like a new house, school, or day care situation, could trigger separation anxiety disorder.
- **Stress:** Stressful situations like switching schools, or the loss of a loved one, including a pet, can trigger separation anxiety disorder.
- **Over-protective parent:** In some cases, separation anxiety disorder may be the manifestation of the parent’s own anxiety, parents and children can feed one another’s anxieties.
COGNITIVE BEHAVIOURAL THERAPY (CBT)

What is cognitive behavioural therapy?
(CBT) is a talking therapy that can help you manage your problems by changing the way you think and behave. Its most commonly used to treat anxiety and depression, but can be useful for other mental and physical health problems. Ask your GP for a referral.

British Association for Behavioural and Cognitive Psychotherapies
www.babcp.com/Public/What-is-CBT.aspx
Information on CBT and how to find a therapist

Free Online Cognitive Behavioural Therapy

COPING MECHANISMS AS A PARENT CARER

If your child displays challenging behaviour and you find it difficult to cope, support is available. It is particularly important that you seek support if you are experiencing harm from the person you care for (whether intentional or unintentional). Many organisations for people with learning disabilities have strategies for coping with challenging behaviour. Some of these organisations also provide opportunities for carers to connect with other people in a similar situation – for example, through family linking schemes. Sharing your experiences, for example, with a local carers’ group can be a good way of getting support. Contact the Carers Direct helpline on 0300 123 1053 or contact your local Carers support organisation. Talk to other Unique parents to ask how they cope. Sometimes other parents are the best source of information and they may come up with something you haven’t already tried. Talk to your GP or paediatrician or social worker to see if they can offer additional support. Sometimes parents just need a break, so don’t be afraid to ask for some respite care/short breaks. You may be entitled to a carer’s assessment for yourself. Have a read of our guide on Carers wellbeing, which is available to download from our website, in the family information guides section.  http://bit.ly/2vmvKUZ
BEHAVIOURAL LINKS........................

♦ ANXIETY UK  www.anxietyuk.org.uk/
Anxiety UK is a charity for those affected by anxiety disorders.
Infoline: 0844 775 774  Email: support@anxietyuk.org.uk

Supporting parents and carers: a trainer’s guide is intended to provide parents and carers, with materials to deliver training in positive behaviour strategies.

♦ CAMHS (Child Adolescent Mental Health Services)
http://bit.ly/1V4pzKQ
What is CAMHS? CAMHS are specialist NHS children and young people’s mental health services. If you think your child might need more help than friends, family, school and GPs can give, please visit the Young Minds website above. CAMHS can help with violent or angry behaviour, depression, eating difficulties, low self-esteem, anxiety, obsessions or compulsions, sleep problems, self-harming and the effects of abuse or traumatic events. CAMHS can also diagnose and treat serious mental health problems. The YoungMinds Parents’ Helpline is a telephone and online support service, they do not support families face to face, or provide mental health assessments. You will need to get a referral to your local CAMHS.
How do I get referred to CAMHS?
• Speak to your GP or school who can refer your child to CAMHS
• Search online for ‘Child and Adolescent Mental Health Services’ in your area - your local NHS trust website should have the details.

♦ CEREBRA GUIDES
http://w3.cerebra.org.uk/help-and-information(guides-for-parents/
Cerebra have some excellent guides for parents on their website, Including:
• Anxiety Guide: A Guide for Parents
• Arrest and Detention of Disabled Children: A Guide for Parents
• Managing Challenging Behaviour Factsheet
• Pain: A Guide for Parents
This network is for families caring for, or individuals with **severe or profound learning disabilities** (both children and adults) who typically display behaviour which may put themselves or others at risk or which may prevent the use of ordinary community facilities. The Challenging Behaviour Foundation produces a range of factsheets on their website, including:

- Difficult Sexual Behaviour in boys with Severe learning disabilities
- Pica (Eating inedible objects)
- Self-Injurious Behaviour
- Understanding Challenging Behaviour

Their Family Support Service offers a listening ear and provides free information about challenging behaviour to anyone who supports someone with a severe learning disability. The Challenging Behaviour Family Linking Scheme will try to link you with another family who are experiencing or, who have experienced some of the same issues as yourself.

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**FAMILY LIVES**  [www.familylives.org.uk/](http://www.familylives.org.uk/)

Helpline: 0808 800 2222 24 hour helpline on all aspects of parenting. Family Lives offers a confidential helpline service which is free from landlines and most mobiles (previously known as Parentline).

Information, advice, guidance and support on any aspect of parenting and family life, including bullying.

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**FIND (Further Inform Neurogenetic Disorders)**  [www.findresources.co.uk](http://www.findresources.co.uk)

This website summarises findings from high quality research studies into genetic syndromes. This website was built by the Cerebra Centre for Neurodevelopmental Disorders in partnership with Cerebra, Economic and Social Research Council and syndrome support groups to reduce the amount of time it takes research findings to reach parents, carers and professionals – the people who need the information the most.

The work of the Centre focuses on the difficulties experienced by children and adults who have intellectual disability, autism spectrum disorders and genetic syndromes that are associated with developmental delay.
LIVING LIFE TO THE FULL  www.livinglifetothefull.com  
Free online life skills course for people feeling distressed and their carers. Helps you understand why you feel as you do and make changes in your thinking, activities, sleep and relationships.

MENCAP  www.mencap.org  
Helpline: 0808 808 1111 (Mon-Fri 9am-5pm)  
Northern Ireland: 02890 691351  Cymru: 02920 747588  
Email: help@mencap.org.uk

MIND  www.mind.org.uk  
0300 123 3393  Monday to Friday (except for bank holidays). 9am-6pm  
Email: info@mind.org.uk  
MIND is the Mental Health charity. It has a variety of useful leaflets available to download or purchase from its website.

MINDED  www.minded.org.uk  
MindEd is a free e-learning resource to help adults to identify and understand children and young people with mental health issues. It is aimed at everyone with a duty of care for children and young people, whether this be through their work or outside it in a voluntary or charitable capacity. This could be as a counsellor, teacher or police officer, an athletics or football coach, or through involvement with the Scouts or Brownies. MindEd has something for everyone.  
How does it work? MindEd offers short (no more than 20-30 minutes) online learning sessions, to help adults identify mental health problems (looking at how problems manifest themselves through particular feelings or behaviours) and demonstrate what action to take in the best interests of the child or young person. These sessions can be completed as a ‘one off’. Visitors can sign up as MindEd members and complete several sessions which they can record on their personal page and print as a certificate for their learning record.

MOOD GYM  http://moodgym.anu.edu.au  
An Australian based website providing free online CBT resources with an interactive programme, that helps you to identify and overcome problem emotions, helping to prevent and decrease depression, using information, quizzes, and skills training.
NATIONAL CHILD AND MATERNAL HEALTH INTELLIGENCE NETWORK  www.chimat.org.uk/camhs
ChiMat do not provide direct services to families. But have links on their website to information and support.

NICE guidelines on anxiety disorders
www.nice.org.uk/guidance/qs53

PBIS (Positive Behavioural Interventions and Supports)
www.pbis.org/
US based organisation.

PHOBICS SOCIETY  www.phobics-society.org.uk/
A website that helps provide information to people who suffer from a phobia or anxiety disorder.

POSITIVE BEHAVIOURAL SUPPORT (PBS)
www.pavingtheway.works/resources
Resources for Family Carers, available free online. The Paving the Way website, includes a free set of Positive Behavioural Support resources for family carers.

PSYCHNET-UK - Mental Health & Psychology Portal

020 7235 2351
General enquiries email: reception@rcpsych.ac.uk
The website has a large variety of useful leaflets and information for families on all aspects of mental health.

SOCIETY FOR THE STUDY OF BEHAVIOURAL PHENOTYPES
www.ssbp.org.uk/
01628 528 901   Email: ssbpliz@gmail.com
A useful contact for professionals. The Society for the Study of Behavioural Phenotypes. (SSBP) is an international, interdisciplinary research society for studying the learning and behavioural problems of individuals with genetic disorders.
Triple P is a parenting programme, but it doesn’t tell you how to be a parent. It’s more like a toolbox of ideas. You choose the strategies you need. You choose the way you want to use them.


● YOUNG MINDS
https://youngminds.org.uk/
0808 802 5544 Mon to Fri 9.30am-4pm
Email: enquiries@youngminds.org.uk
YoungMinds provides information to parents and professionals. It produces leaflets on various topics, a directory of child guidance, psychiatric and psychological services and a newsletter.
**BOOKS**

**Beyond Words by Sheila Hollins**
https://booksbeyondwords.co.uk/

*Beyond Words* is a provider of books, services and training for people who find pictures easier to understand than words. Whether supporting somebody with a learning disability or communication difficulty, these books empower through pictures.

**Functional Behavior Assessment for People with Autism** (Topics in Autism) by Beth Glasberg. Available to purchase from Amazon http://amzn.to/2tHCTkQ and other retailers.

Parents and professionals caring for people with autism sometimes encounter baffling, challenging behaviour noncompliance, aggression, or repetitive actions which they don’t know how to stop. The key to resolving problem behaviour is to first determine its purpose by conducting a functional behaviour assessment (FBA).

**Helping children who are anxious or obsessional.**
A guidebook by Margot Sunderland & Nicky Armstrong to help children who:
- are insecure or worry too much,
- suffer from phobias or nightmares,
- find it difficult to concentrate to let go and have fun,
- have suffered a trauma,
- are worryingly good or seem like little adults,
- use order and routine as a way of coping with ‘messy’ feelings,
- retreat into dullness as a way of managing their being in the world,
- develop obsessive-compulsive behaviour in order to ward off their too-powerful feelings.

It is available to buy from http://bit.ly/2h2EN66

**How to manage children’s challenging behaviour**
by Bill Rogers. Available to purchase through Amazon http://amzn.to/2hivZZu and other retailers. Dr. Bill Rogers taught for many years before becoming an education consultant and author; he lectures widely on behaviour management, discipline, effective teaching, stress management and teacher welfare across the UK and
Europe, Australia and New Zealand. Bill also works as a mentor-teacher, team-teaching in challenging schools. He is well aware of the challenges of teacher leadership in schools today. In this edition of his bestselling book, Bill Rogers brings together contributions from practising teachers that suggest ways to tackle disruptive and challenging behaviour. Bill introduces and comments on each chapter, setting out key principles for behaviour leadership in the style that makes him such a popular author. There are numerous case studies drawn from practice, each showing how the teacher manages the situation and what the outcome was: these examples from practice highlight the difference teachers can make to their students' behaviour, attitude, self-esteem and peer acceptance. Chapters look at: finding a way back from inappropriate behaviour; dealing with very challenging behaviour on a daily basis; creating a peaceful school and developing positive practice.

Jessica Kingsley Publishers www.jkp.com
020 7833 2307 Email: post@jkp.com Jessica Kingsley have a huge variety of books on behavioural problems, disability, practical, legal, social issues, therapies etc. You can also contact them by phone for a brochure.

Living life shop http://shop.llttf.com/llttf-resources/llttf-books
Living life has a useful selection of booklets including: “Why do I feel bad?” and “Are you strong enough to keep your temper?”

Stop That (Seemingly) Senseless Behavior!
Fba-Based Interventions for People with Autism (Topics in Autism) by Beth A. Glasberg. Available to purchase from Amazon http://amzn.to/2soMicX and other retailers. A guide to developing an effective behaviour intervention plan to stop undesirable behaviours such as hitting, screaming or repetitive questioning. It outlines an educational approach for parents, teachers and service providers that not only reduces the problem behaviour but also teaches the individual with autism new skills to get his needs met.
Supporting the highly sensitive child: Making sense of Meltdowns by James Williams and Lucy Skye. This simple, concise book steps beyond a basic understanding of high sensitivity, looking at the challenges and distress that meltdowns can cause for highly sensitive children. And for you. Available from Amazon.

The Special parent’s handbook http://yvonnenewbold.com/ by Yvonne Newbold
email: yvonne@yvonnenewbold.com
Yvonne Newbold is a writer, speaker, workshop facilitator and consultant in issues relating to disability who has written a book named the special parent’s handbook based on her experiences of bringing up her own disabled children.

Understanding and Supporting Children with Emotional and Behavioural Difficulties By Paul Cooper. This is a comprehensive guide to some of the difficulties and disorders which can cause children to become disruptive at school and in the home. It examines the nature of EBDs and their potential causes, whether social, psychological or biological and discusses the issues that can arise for professionals involved in their assessment, analysing the various methods used. Available from Amazon and JKP.

“What to do when you worry too much”
What to do when you worry too much: A Kid’s Guide to Overcoming Anxiety by Dawn Huebner, PhD.. A self-help book designed to guide 6-12 year olds and their parents through techniques most often used in the treatment of generalized anxiety. Engaging, encouraging, and easy to follow, this book educates, motivates, and empowers children to work towards change. It is available to buy from Amazon http://amzn.to/2h2G8u3 and other retailers.
SENSORY SENSITIVITIES AND AUTISM

People with autism often have their senses enhanced. A typically functioning person would be able to shut out background sounds and just hear the one sound that they need too. For those with autism, they find it difficult to shut out these additional sounds and often cup their hands over their ears in an effort to block out any noise. People with autism often have difficulty understanding what’s happening around them and communicating with other people.

The autism diagnostic assessment for children and young people

The National Autistic Society www.autism.org.uk
Autism helpline: 0808 800 4104 (lines open Mon-Thurs 10am-4pm, Fri 9am-3pm) Email: nas@nas.org.uk

PDA (Pathological Demand Avoidance)
www.pdasociety.org.uk/what-is-PDA

What is PDA?
Pathological demand avoidance (PDA) is increasingly accepted as a behaviour profile that is seen in some individuals on the autism spectrum. People with a PDA behaviour profile share difficulties with others on the autism spectrum in social communication, social interaction and restricted and repetitive patterns of behaviours, activities or interests. The main characteristic of a PDA behaviour profile is a high level of anxiety when demands are placed on that person. Demand avoidance can be seen in the development of children, including those on the autism spectrum. It’s the extent and extreme nature of this avoidance, together with displays of socially shocking behaviour that leads to it being described as ‘pathological’.
Severe behavioural difficulties
A large proportion of people with the PDA profile can have real problems controlling and regulating their emotions, particularly anger. As children, this can take the form of prolonged meltdowns as well as less dramatic avoidance strategies like distraction and giving excuses. It is essential to see this as extreme anxiety or 'panic attacks' and to treat them as such. Try using reassurance, calming strategies and de-escalation techniques.

As PDA is considered to be a behaviour profile within the autism spectrum, it is usually identified following a diagnostic assessment for autism. Source: www.autism.org.uk/about/what-is/pda.aspx

“One successful idea I had when dealing with M. aged 32 years... He hates being told to clean his room or put things away, e.g. clothes or towels on the floor of his room. I tried explaining that it was dangerous and he might fall, this annoyed him, his response was to scream at me and say "I hate you telling me what to do". So, I sat with him and we devised a special secret action, the action means.....I’m not going to tell you what to do, you already know, this is just a reminder. Ours was quite comical, I’d say "Jellyfish" then wave my arms around and say "bloop, bloop" noises, this always ended with both of us giggling and M. trying to wink at me, give me a thumbs up, and as soon as I left the room (so it didn’t look like I was checking up on him) he’d pick up the things on his floor, he’d then, very proudly call me in to show me...and we celebrated with our secret handshake and hug.”
**PDD**

**What is PDD?**

PDD stands for Pervasive Development Disorder is an umbrella term for the following:

- Autism
- Asperger Syndrome
- Rett Syndrome
- Childhood Disintegrative Disorder

PDD-NOS (Pervasive Developmental Disorder Not Otherwise Specified) used to describe atypical autism.

**PDD-NOS**

**What is PDD-NOS?**

PDD-NOS stands for Pervasive Developmental Disorder-Not Otherwise Specified. Sometimes a child with learning and behavioural differences doesn’t meet all the diagnostic criteria for Asperger Syndrome or Autism, which can lead to a diagnosis of PDD-NOS. Pervasive Developmental Disorder – Not Otherwise Specified is the diagnosis given to those who fall into this category. Some practitioners refer to PDD-NOS as “atypical autism”. Medical journal abstract: [http://bit.ly/2lZtjn9](http://bit.ly/2lZtjn9)

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Never underestimate a child’s ability to get bored or their need for attention. It is impossible for parents to be on constant entertainment duty, so it is useful to prepare something that will keep a child amused for short periods of time. Musical mobiles, interactive toys or DVD’s can help.
What is a sensory issue or sensitivity?

**Sensory Processing Disorder (SPD)** is a condition in which the brain has trouble receiving and responding to information that comes in through the senses. It was formerly referred to as sensory integration dysfunction. Children with sensory processing issues can be oversensitive to sights, sounds, noise, textures, flavours, smells and other sensory input. For many children with a chromosome or genome disorder ‘sensory issues’ can be a problem and cause behaviour which challenges. For example:

- They might hate the labels or seams in their clothes; they might find them itchy or unbearable.
- They might hate to be touched in any way, i.e. having their face and hands or their hair washed, or even dislike the shampoo and/or water running down their face, shoulders or back.
- They cannot touch or eat certain foods.
- They might be sensitive to certain smells, odours.
- They might hate being tickled or cuddled.

For some children these types of behaviours can be managed by cutting labels out of clothes or buying seam free clothing, or finding a way of shampooing hair where the water and soap doesn’t touch another part of their body.

**Sensory overload** occurs when one or more of the body’s senses experiences over-stimulation from the environment. There are many environmental elements that impact an individual. Examples of these elements are crowds, noise, media and technology.

- They hear too much noise (most people have a way of shutting out certain noises, but children and adults with sensory problems, can hear lots of noises all at once and have difficult shutting off those extra noises).

For those that find sounds, or noise difficult to cope with, noise reducing headphones can help to minimise what they hear.
“My son has problems with noise, often putting his hands over his ears to block out sounds. We bought him some noise-cancelling headphones, which have helped him cope in ‘difficult’ situations.”

DEVELOPMENTAL PATHWAYS FOR KIDS
http://bit.ly/2tKjNGC
USA based clinic that has lots of useful resources including a checklist, on its website.
**FAECAL SMEARING**

**What is faecal smearing?**

It sounds horrible, but for some younger children playing with their ‘poo’ could mean that they are ready for toilet training and they are inquisitive about how their body functions. For other children/adults- engaging in smearing faecal matter can be a form of attention seeking or, can serve as a sensory input need, or they might just be feeling unwell. As with many challenging behaviours, it is important not to show too much of a negative reaction, but to reward good behaviour with consistent, positive praise. That way a child will learn which behaviours earn positive attention or rewards.

**What can I do to stop my child from smearing?**

- Dressing them in clothing that makes access to their back area difficult. i.e. pyjamas with a back fastening zip or buttons, a onesie or full body vests that do up underneath the bottom can help.
- Reading them a social story which reinforces the routine of toilet hygiene.
- Messy play to help with the sensory input
- Scent: smell strong smelling food like cheese, or playdoh that is scented
- Touch: playdoh, theraputty
- Visual: finger painting; shaving foam

“J went through a stage of smearing; he would smear all over his bedroom walls. I was at my wits end. However, when I was advised that it might be sensory and that J. may be seeking sensory overwhelm, I was given advice to give him some cloth with Olbas oil. I just used heavy duty kitchen roll and applied about 5 drops of oil which creates quite a strong scent. J. would hold it to his nose and enjoy the strong aroma. Amazingly it worked and over time I reduced the amount of oil I used. Miraculously the smearing stopped!!!”

BRUSHING AND JOINT COMPRESSIONS

Many of our parents – particularly in the USA, have used this type of therapy for sensory defensiveness. It might not work for everyone but for some it has been helpful. You can find out more about this technique here: http://bit.ly/1WGt1A1

The Wilbarger Protocol (Brushing Therapy) for Sensory Integration is a specific, professionally guided treatment regime designed to reduce sensory defensiveness. The Wilbarger Protocol is a deep pressure technique used with children who have sensory defensiveness. It has its origins in sensory integration theory, and it has evolved through clinical use. It involves deep-touch pressure throughout the day. Patricia Wilbarger, M.Ed., OTR, FAOTA, developed this technique. There is a video of a mum putting this technique into practice here: Wilbarger Brushing Protocol (OT Brushing & Joint Compressions) http://bit.ly/2msPMMT
ORAL MOTOR DEVELOPMENT

What is oral motor development?

Oral motor development refers to the use and function of the lips, tongue, jaw, teeth, and the hard and soft palates. The movement and coordination of these structures is very important in speech production, safe swallowing, and consuming various food textures. You can have either hypo-sensitive or hyper-sensitive oral motor. Signs that a child is hyper-sensitive typically include dislike of brushing teeth, having their faces wiped, and are usually very picky eaters especially with specific textures. They can be very fussy about what they eat. They might dislike certain foods because they look odd (to them) or taste odd.

- **PATHWAYS** [www.pathways.org](http://www.pathways.org)
  A U.S.A based website with lots of useful information on children’s sensory development.

- **MAXIMUM POTENTIAL** [www.maximumpotential.eu/](http://www.maximumpotential.eu/)
  0207 486 4747
  A clinic specialising in Sensory Integration and Neurodevelopmental Therapy.

- **SENSORY DIRECT** [www.sensorydirect.com/](http://www.sensorydirect.com/)
  For all things sensory, including weighted blankets, fidget toys, clothing, etc.

- **SENSORY INTEGRATION NETWORK** [www.sensoryintegration.org.uk](http://www.sensoryintegration.org.uk)
  On Facebook: [www.facebook.com/SensoryIntegrationNetwork/](http://www.facebook.com/SensoryIntegrationNetwork/)
  UK- 0118 324 1588 Email: support@sensoryintegration.org.uk

What is sensory integration? Sensory integration is about how our brain receives and processes information so that we can do the things we need to do in our everyday life.

- **SENSORY PLANET** [www.facebook.com/groups/2217476670/](http://www.facebook.com/groups/2217476670/)
  Sensory issues discussion group.
SENSORY PROCESSING DISORDER – PARENT SUPPORT
https://sensoryprocessingdisorderparentsupport.com/
Some really useful information on all different types of sensory behaviour

SENSORY TOYS/ACTIVITIES/SENSORY ROOM

♦ FLEDGLINGS  www.fledglings.org.uk
01799 541 807 Email: enquiries@fledglings.org.uk
Fledglings understand that life with a disabled child can be challenging, and help by providing practical, affordable, good quality products that address everyday problems faced by children with disabilities such as chromosome and genome disorders.

♦ SENSORY TOY WAREHOUSE  www.sensorytoywarehouse.com/
A Multi Award Winning innovative company, specialising in inspiring sensory activities, toys and equipment.

♦ SENSORY PLUS  www.sensoryplus.co.uk/
SensoryPlus Ltd is an independent sensory equipment provider from single catalogue items through to entire environments.

♦ SENSORY TRUST  garden ideas http://bit.ly/2gMJW6D
The Sensory Trust is a leading authority on inclusive and sensory design. They use nature and the outdoors to improve the health and wellbeing of people living with disability and health issues, their families and carers. They work throughout the UK, and share their approaches internationally with a wide network of organisations and individuals.

♦ SPD STAR  www.spdstar.org/
STAR Institute Treatment Center customize approaches for specific sensory challenges that you and your child experience. U.S.A based.

♦ SPECIAL NEEDS TOYS  www.specialneedstoys.com/uk/
01299 827820 Email: info@specialneedstoys.com
Special Needs Toys, and other sensory items.

♦ UNDERSTOOD is a free resource for parents and carers (U.S.A based)
http://u.org/2lXloaj
WEIGHTED THERAPY - BLANKETS, PADS, COMPRESSION VESTS

Weighted blankets are a sensory tool that Occupational Therapists often recommend for children and adults with Attention Deficit Hyperactivity Disorder, Sensory Processing Disorder, Anxiety and Autism Spectrum Disorders to assist with calming and sleep. You can get weighted blankets, lap pads, compression vests, and pressure clothing from many different companies online. You can find them using search engines, but be careful where you buy from.............

It is recommended that the weighted blanket should not exceed 10% of the users bodyweight. Please follow guidelines for safety.......
LYCRA BED SOCK  http://bit.ly/2u9t2nl
A couple of ‘Unique’ families have purchased a Lycra bed sock. It is designed for children/adults who have a difficult time unwinding, relaxing, and calming their body for sleep.

YOGA FOR CHILDREN AND ADULTS WITH SPECIAL NEEDS
Yoga can help children and adults with special needs to relax and de-stress as well as helping to strengthen and tone their muscles. There is a huge variety of different types of Yoga, so it might be a case of contacting yoga teachers and talking to them about your child’s needs. For more information:
♦ www.specialyoga.org.uk
♦ www.specialyoga.com

Special needs article about yoga for people with disabilities http://bit.ly/2virHsS

No parent is perfect and no child is perfect.
Everyone has good and bad days
A famous Chinese proverb says: “A journey of a thousand miles begins with a single step.” Managing difficult behaviour may be a long journey but you only have to start with that single step.
Inform Network Support

Rare Chromosome Disorder Support Group
The Stables, Station Road West, Oxted, Surrey RH8 9EE,
United Kingdom
Tel: +44(0)1883 723356
info@rarechromo.org | www.rarechromo.org

Join Unique for family links, information and support. Unique is a charity without government funding, existing entirely on donations and grants. If you can please make a donation via our website at www.rarechromo.org we would be very grateful.

Our thanks to all of our parents for their contributions to this guide. Any treatments in this guide are not endorsed by Unique, the details have been given for information purposes only. This guide was compiled by Unique and reviewed by Dr Caroline Richards PhD, ClinPsyD, Lecturer in Neurodevelopmental Disorders and Dr Jo Moss, Research Fellow at the Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham, Birmingham B15 2TT www.cnndd@bham.ac.uk

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